

CHES:

An Interactive Computer System For Women With Breast Cancer Piloted With An Under-Served Population

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ABSTRACT

The Comprehensive Health Enhancement Support System (CHES) is an interactive computer system containing information, social support and problem solving tools. It was developed with intensive input from potential users through needs-assessment surveys and field testing. CHES had previously been used by women in the middle and upper socio-economic classes with high school and college education. This article reports on the results of a pilot study involving eight African-American women with breast cancer from impoverished neighborhoods in the city of Chicago. CHES was very well received, extensively used and produced feelings of acceptance, motivation, understanding and relief.

are critical. While health care providers inform patients about their diagnoses and possible treatments, they have limited time to convey the necessary information. Patients are asking for more information, given in a way that is easily understood and in increments that are not overwhelming. Access to the information and social support needed to cope with breast cancer can be difficult to obtain. Geographical barriers, limited accessibility to existing services, limited financial resources, and the complexity of the disease and its treatment hinder women from getting the information, problem-solving tools and social support systems they need. The Comprehensive Health Enhancement Support System (CHES) was designed to overcome these barriers [7].

INTRODUCTION

A diagnosis of breast cancer often creates a crisis for women and their families [1,6]. According to crisis theory, people often experience depression, fear, guilt, and helplessness during a health crisis because their former coping strategies are no longer effective [2,9]. Research indicates that information and emotional, social and spiritual support play a key role in helping patients cope [1,3,5,11]. This can lead to more accurate expectations [4], improved physical health, and improved survival rates [1,5,11]. Information and support also improve the physical and emotional health of breast cancer patients and their primary caregivers [6].

With the increased pressure to contain health care costs, more effective ways of providing information, support, decision and problem solving tools for patients

OVERVIEW OF CHES

CHES is an interactive computer-based system designed on the premise that successful response to a medical crisis requires information, social support, and decision-making and problem-solving skills. People have different needs and learning styles and therefore seek different ways to solve their problems throughout the crisis[13,14]. CHES' user friendly interface addresses the research findings that information and support is most valuable when it meets the following criteria: it is convenient, comprehensible, affordable, timely, non-threatening, anonymous, and controlled by the user [1,9-12]. For instance, some people prefer structured decision-making help that leads them through analysis of options, decision criteria, values and perceptions. Others read the literature, or interact with other women who have made similar decisions. CHES is a flexible system offering a wide variety of mechanisms to meet the needs of people

in a health crisis. CHESS modules have been developed for Breast Cancer, AIDS/HIV Infection, Substance Abuse, Sexual Assault, and Academic Crisis. A brief description of the components and services of the CHESS Breast Cancer Module follows.

Information Components:

Questions and Answers (QA) is a compilation of brief answers to many common questions about breast cancer. Users have the option to link to more in-depth information within the CHESS Instant Library.

Instant Library (IL) is a collection of over 100 articles drawn from scientific journals, newsletters, brochures, pamphlets and the popular press on breast cancer and related issues.

Ask an Expert (AE) allows users to anonymously ask questions about breast cancer and receive an answer within 48 hours.

Getting Help/Support (GH) is a tutorial that helps users understand how to find a good provider and how to be an effective consumer. The tutorial also provides sample wordings of how to set up an appointment or talk with a health care provider.

Social Support Components:

Discussion Groups (DG) provides a non-threatening place to communicate anonymously with other women affected by breast cancer. Discussion groups are available for women with breast cancer, partners of women with breast cancer, and other special groups.

Personal Stories (PS) are real accounts of women affected by breast cancer. Our research team interviewed patients, partners, and adult children for personal descriptions of their experiences and how they coped with breast cancer. These stories represent a wide range of experience and background.

Problem Solving Components:

Decisions and Conflicts (DC) uses utility theory to help people think through difficult decisions such as what surgery to have and whether to take adjuvant chemotherapy or tamoxifen treatment. Users can read a description of each option or read an excerpt from the personal story of a woman who chose that option. They can read about criteria other women considered in making the choice, why each may be an important consideration for them, what research says about their choices, and how each concern affects each criterion.

Action Plan (AP) combines statistical decision theory and change theory to help users think through how to implement a decision they have made. It is one thing to decide to adopt a low fat diet, and yet another to implement a decision in the face of ingrained habits or family pressures. This program asks users thirteen questions about their plan to implement a decision. Using the results, it predicts the likelihood of success in the implementation of the plan. It also identifies ways the user can strengthen her prospects for successful implementation.

CHESS is reviewed and updated biannually. Our system allows us to post particularly newsworthy or significant information at any time. In the recent case of falsified data regarding lumpectomy and mastectomy surgery, we updated CHESS immediately and kept people informed of the latest findings and reports. This easy update feature allows users access to the most recent information and discoveries about breast cancer and can ease the fears and concerns that can arise from uncertainty.

CHICAGO PILOT STUDY

Our most recent pilot study of the CHESS breast cancer module consisted of eight African-American women in impoverished neighborhoods of inner city Chicago. Through the efforts of the Midwest National Black Leadership Initiative on Cancer, Cook County Hospital agreed to participate in this study. This study took place between 10/1/93 to 1/15/94. All of the women were stage I or stage II breast cancer patients. They were contacted by a patient advocate from Cook County Hospital and asked if they would be willing to participate in a pilot study of CHESS. This was strictly voluntary, with no financial compensation for the participants.

Twenty women were offered CHESS, thirteen agreed to have it in their home (65% acceptance rate). However, five women changed their minds and decided not to take part in the study between the time of their original agreement to participate and when they were contacted to schedule a time to place the computer in their home. This recruitment rate (40%) is much lower than what we have experienced in other pilot studies (over 80% acceptance rate). We believe this may be due to a four to six week delay between the time the women initially agreed to be in the study and scheduling computer installation in their home. In previous studies

once the woman agreed to participate the computer was placed in her home within one week.

The age of the women ranged from 36 to 66 years old. Six of the eight women were 55 or younger. All of the women were single (either divorced, separated, widowed or never married) at the time of the study. Half had never completed high school and only three of the eight women had any prior computer experience. All of the women were on public assistance. Five of the women had had lumpectomies and two had had mastectomies within the past year (5 had surgery in the past six months). Only one woman had CHESS prior to deciding what surgery to have.

A computer was installed in the home of each woman by a CHESS staff member, who gave approximately one hour of instruction and orientation. Use data was automatically collected by the computer and one survey was mailed to each participant.

CHESS was used 886 times within the 15 week access period (Table 1). "Use" was defined as an entry lasting at least a minute into a CHESS service. On average, each woman used CHESS 7 times per week and was on the system for more than one hour per week.

Table 1: Cook County Study: Use of CHESS Services

Service	# of Uses	Minutes
Discussion Group	442	5046
Ask an Expert	227	1487
Questions & Answers	83	617
Personal Stories	43	504
Instant Library	48	341
Decisions & Conflicts	20	208
Getting Help/Support	18	76
Action Plan	5	48

In the Chicago Pilot Study involving 8 African-American women, 55% of the total time of use was in the Social Support Components (Discussion Group, Personal Stories), 41% in the Information Components (Ask an Expert, Instant Library, Questions and Answers, Getting Help/Support), and 4% in the Problem Solving Components (Decisions & Conflicts and Action Plan).

The use patterns of a previous CHESS pilot study involving 20 Caucasian women from the University of Wisconsin Hospital and Clinics diagnosed with stage I or stage II breast cancer indicates that 67% of their use was in the Social Support Components, 31% in the Information Components and 2% in the Problem Solving Components of CHESS (Table 2).

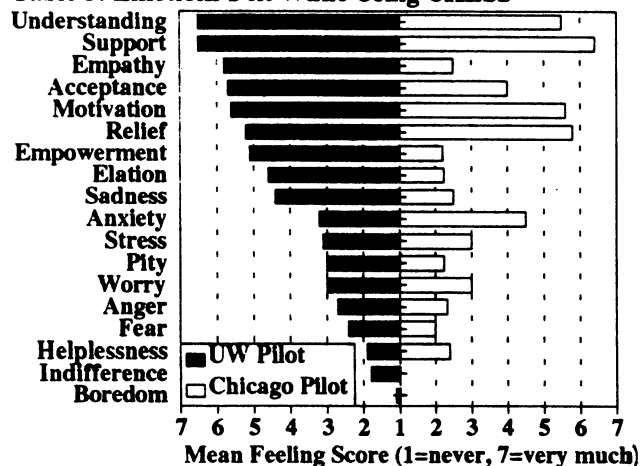
Table 2: Usage of CHESS Components, by Percentage of Total Uses, of Two Study Populations

CHESS Component	Cook County	UW Hospital
Social Support	55 %	67 %
Information	41%	31%
Problem Solving	4 %	2 %

As in previous studies involving HIV+ men who used CHESS, African Americans tend to use the Support Component of CHESS less than the Caucasian participants, while using the Information Components more[7]. It is unclear at this point what accounts for this difference. Further study of various ethnic populations' use patterns of CHESS are needed to determine what accounts for the difference and if specialized adaptations of CHESS are required to meet the differing needs of various populations.

In the follow up survey from the Chicago Pilot (returned by 5 of the 8 women) the women indicated that they felt acceptance, motivation, understanding, and relief while using CHESS (all over 5.0 on a 7 point scale). They experienced low levels of negative emotions such as stress, boredom, fear, sadness, indifference, helplessness and anger (all less than 3.0 on a 7 point scale). Elation and empowerment were low (2.25 and 2.2), while anxiety was relatively high (4.5). This finding is opposite what we have found in previous studies, where women felt empowered and their anxiety level was low (Table 3). Many of the written comments by the African-American women seem to agree with our previous studies however, leading us to believe that the term 'empowerment' and 'empathy' may have been misunderstood.

Table 3: Emotions Felt While Using CHESS



Questions regarding the value and ease of use of CHESS were rated on a 1-7 scale (7 being very valuable or very easy to use). The overall value of CHESS was rated 7.00, with only three of the services being rated below 7.00. Action plan was rated the lowest at 6.50.

Action plan was also rated the lowest in terms of ease of use (4.80), however overall CHESS was rated 5.80. Six of the eight CHESS services were rated above 6.00 in ease of use. Despite the relatively lower ease of use score of Discussion Groups (5.25), this service was used more extensively than any other CHESS service (Table 4). CHESS appears to be extremely user-friendly and lack of computer experience is not a barrier to use. Five of the eight women in this pilot had never used a computer prior to CHESS.

Table 4: Ease of Use & Value (0 - 7 scale)

Service	Ease of Use	Value
CHESS Overall	5.80	7.00
Questions & Answers	6.75	7.00
Instant Library	6.75	7.00
Getting Help/Support	6.00	6.75
Personal Stories	6.60	7.00
Ask an Expert	7.00	7.00
Discussion Groups	5.25	7.00
Decisions & Conflicts	6.75	6.67
Action Plan	4.80	6.50

Other results indicate that there has been a reduction of depression and isolation. The following message was left in the CHESS Discussion Group by a woman in the Chicago Pilot Study using the code name Barbara:

"I feel sad and lonely a lot and all my so-called friends that I thought I had have all turned their backs on me. So I really don't know how to deal with it. Can you please tell me what I should do? I get really depressed sometimes and sometimes I feel like taking my life just to end it all. Why should I feel that way? I don't even know how to deal with this. Some people say to me girl, I know what you are going through and I get upset because I tell them that they do not know anything because this hasn't happened to them. They have never had a breast removed but I have. And the so called friends I had in my corner were not there for me. So I'm saying this to say I need someone to talk to before I crack up."

Within 24 hours Barbara received four messages from other women in the pilot test as well as the discussion group facilitator. While not all women experienced the depth of pain Barbara felt, many had similar experiences of isolation and misunderstanding by those close to them.

The women who had CHESS became change agents in their community. As they learned more about breast cancer, they began to talk to others in their community and became a resource for them. There were also 10 known secondary users (family members, friends, or neighbors) in the Chicago pilot. The use data of these secondary users is not included in this paper.

CHESS provided an opportunity to get information, support and problem-solving tools to this under-served population in the convenience of one's own home. The following quotes are from two of the Chicago pilot study participants:

"I learned more about my cancer from CHESS. It was very informative. I also learned that there are people who care about others."

"I had a computer that I could take my time with and get answers."

The barriers (geographic location, cost, child care...) that had prevented these women from accessing information and support were easily overcome by their in-home use of the CHESS computer.

CONCLUSION

This pilot study confirmed that a computer system is a viable option for an under-served population. In a health care system which is desperately trying to contain cost, CHESS can help ease the load of doctors and patient advocates, while allowing women to take back control of their lives. CHESS can allow health care providers (patient advocates, doctors, nurses...) to more efficiently track patients, maintain better communication, and make better use of their time.

While these results are only preliminary and with a limited number of users, we are very encouraged. These results reinforces the need for more extensive studies to determine CHESS' effectiveness in meeting the decision, information, and emotional needs of women diagnosed with breast cancer in under-served populations.

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